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ABSTRACT

This case study describes the recent development of two housing co-ops "Courtyard" and "CHORD," in Toronto (Ontario, Canada) that are inclusive of people with disabilities, that is, the co-ops were developed by people with disabilities, their families, and friends. Focus is on components utilized in the planning and development of the co-ops by their umbrella organization, Neighbors Allied for Better Opportunities in Residential Support (NABORS). The report is based on a site visit in April 1994 to the first of the co-ops, open for 10 months at that time. Background information notes the importance of the involvement of people with disabilities, parents, and advocates, and the value of the co-op as an intentional community, not just a housing co-op. A section on co-op organization describes the two co-op housing complexes and the support organization, including their boards of directors, a vision statement, co-op subsidies, membership issues, and allocation of government aid. A statement of principles addresses issues of community, natural social support, membership participation, self-determination, and nondiscrimination. Another section provides quotes from personnel involved in the development of intentional community. The study concludes with a statement emphasizing the importance of organizational clarity, intentional community, full participation for everyone, and relationships. (DB)

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IN TORONTO

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NOT JUST A PLACE TO LIVE:

BUILDING COMMUNITY IN TORONTO

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June 1997

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BUILDING COMMUNITY IN TORONTO

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Introduction

In the past several years, increasing numbers of people with disabilities have moved out of specialized housing (e.g., group homes, community residences) into their own homes in the community. One of the options that some people have chosen is cooperative housing; that is, housing which is collectively operated by and for the mutual benefit of the people who live there. However, living in a co-op, itself, does not mean someone is a full participant in the co-op community. In many cases, people live in co-ops but are not fully included. However, some collaborative efforts between support organizations and co-ops have enhanced opportunities for participation and inclusion.

This is a case study of the development of two housing co-ops in Toronto that are inclusive of people with disabilities--that is, development of the co-op together with people with disabilities, and their families and friends. The co-ops--Courtyard and CHORD--were developed by a group of people who also formed another organization, Neighbours Allied for Better Opportunities in Residential Support (NABORS), which serves as a vehicle to generate support for participation of members who have disabilities.

This paper is based on a site visit in April 1994. At that time, Courtyard had been open for about 10 months (since July 1993) and CHORD was under construction and due to open in the summer of 1994. The primary focus of this paper is on various components that were utilized in the planning for and development of this these co-ops. It is presented not as a model for other groups to follow, but rather to share ideas, strategies, and struggles with others who may be engaged in or interested in pursuing similar efforts.

Background

The effort to create these co-ops emerged out of the connections made between a number of people with disabilities, parents of people with disabilities, and friends. For at least 10 years prior to this, several people with disabilities had been actively meeting and sharing their visions for the development of new options in supported housing that would be more inclusive and less regulated and controlled by the service system.

At the same time, a handful of parents, dissatisfied with the current service system, were making efforts to create alternatives. For example, Gillian Chernets, one of the founders, had come to realize that it was the relationships in her daughter's life that would be more important than just the place she lived. She recognized that "not enough work was being done on the relationship end of things." She reflected:

> I began to sort of think about how somebody could live in a community and not just live there but really work at that sort

> of supportive environment. I had had some experience in Australia with co-ops, and realized there was something in that cooperative manner of doing things that might be a way of improving the lives of people with disabilities.

Gillian contacted the provincial Cooperative Federation (an organization which develops policy guidelines for co-ops and provides information and technical assistance regarding co-op development) to explore the use of the co-op model of housing for people with disabilities.

Others, who were advocates and allies with people with disabilities, had recognized the many problems inherent in the service system, and they were interested in helping create supports for people with disabilities that were less programmatic, less regulated and bureaucratized, and more controlled by people with disabilities themselves. At the same time, they had become interested in cooperative housing, both for themselves, and as a potential source of community for people with disabilities.

With the coming together, in 1989, of these three groups of people--those with disabilities, parents, and advocates--specific plans for a co-op were generated. Their vision for this co-op was based on problems they had seen with social connections within other co-ops. As Beth French, NABORS coordinator and member of CHORD cooperative, put it:

> I had the experience of living in a co-op where an organization had a group home and people were living in the co-op in their own unit, but where they weren't

> integrated. In fact, at the beginning they were more involved, and then over time it really dropped off. Because I remember in the beginning being quite impressed that a lot of the members who'd never had a connection with people previously were quite involved in people going to church together, making sure they got to meetings...So, the spirit was pretty good in the beginning. But, the spirit just kind of died out...and then all of a sudden one day the agency decided to move the original people out and new people moved in, and I was horrified. And, those people were even less connected. And then they just moved out of there altogether. So, that was a good example of how you can practice the concept of integration, but unless you add some support, it just won't work.

Gillian's experiences led her to similar conclusions about lack of support for people with disabilities to participate in most co-ops:

> And, in looking and finding out a little about some people with disabilities who were supported by agencies to live in co-ops, and that happens a lot here, those people were still pretty marginalized. There was no expectation, really, for them to participate. Nobody ensured they participate. So, I wanted to see if we could develop something where

> participation for everybody was the uppermost goal, so that people with disabilities would have an expectation to participate that was no different than anybody else, and that they would be supported to participate. Because that was the key.

Gillian continued, sharing a story exemplifying, in a negative way, what she envisioned for this co-op:

> Greg lived with Ed in a co-op, and Ed had to go to hospital. Greg has one kidney and an in-dwelling catheter, so one of the things he has to do is drink water on a regular basis, and Ed helps him with that. So, Ed goes into hospital, and I thought, shoot, we've got to solve the water problem, cause Greg's attendant leaves at 5:30 or 6:00 at night. And he needs the water at 9:30 or 10:00 at night. So, I went down to the coordinator of the co-op, and I said look, we got this problem, could we find somebody in the building to just step in and get Greg a glass of water. She said, "I doubt it." I said, "What! I doubt it." So, two weeks later we still hadn't found anybody. So, in the end, I knocked on the neighbours' door. And, they said they would do it for two

> weeks, but not more than two weeks. That kind of co-op is not what we want. We've got to do something more proactive than just develop a co-op.

Thus, they wanted to do something different, something that would help connect people more intimately. These experiences had given them the vision for what they wanted--intentional community, not just a housing co-op; and support for full participation for everybody. The challenge was, how to implement and operationalize these ideas into these co-ops.

Co-op Organization

The Toronto project includes three components--two cooperative housing complexes (Courtyard and CHORD) and the support organization, NABORS. This section provides an overview of the general co-op structure, and the following section elaborates on the mission and intent of NABORS.

Within this project, the first organization to emerge was NABORS, which was incorporated in 1984. Members initially focused their efforts on developing community support networks for a variety of individuals. Then, in 1987, they began work toward development of a housing co-op. Originally, the group envisioned only one building, CHORD, which was planned and eventually constructed at a site in North West Toronto. In the meantime, a building became available that was more centrally located, and some members of the group decided they would rather live there. This was divisive of the group; however, the choice made sense for some people, who wanted to

live closer to the center of the city. Courtyard, the building closer to downtown, opened in July 1993 and has 35 units, which is small by co-op standards. CHORD, which opened in the fall of 1994, has 135 units.

The co-ops were created based on a clear value of inclusion (see Figure 1). As a result of their values, these co-ops have developed some policies that differ from most other co-ops--such as limiting the number of people with disabilities, and asking people to become members and participants in the co-op community before they move in. There is the sense, overall, that the Cooperative Federation has been tolerant of the policies and practices.

Board Three boards of directors were formed--one for CHORD, one for Courtyard, and one for NABORS. The NABORS board was originally the group who shared the founding vision of individualized support and cooperative community (see pp. 11-17 for further description). It has now evolved to be comprised of 12 members, either the individual with a disability or his or her representative. They focus on issues of concern to the NABORS organization, including the two primary areas of individualized personal support and community building.

The CHORD and Courtyard boards have been involved in all aspects of co-op formation from development of a vision statement to decisions about everything from physical design to co-op membership. The Boards are diverse and include people with and without disabilities, parents of people with disabilities, and people representing a variety of racial and ethnic groups. Many of the Board members also live in the co-ops. Prior to the time the co-ops were established, Board members had been working

FIGURE 1

COURTYARD COOPERATIVE - VISION STATEMENT

To create a housing cooperative where members have chosen to foster a community spirit. This spirit is based on neighborliness, mutual respect, and helfulness, with people of all ages, backgrounds, and abilities making commitments to one another, including people with special needs and ensuring that they will have support to be fully active members of the cooperative will be central to life in this community.

Through living and working together for the mutual benefit of the co-op we intend to foster lasting personal relationships for people who have been isolated because of their disabilities.

The cooperative recognizes that each member has unique ideas and skills to offer and must play a valued role in the management and day-to-day life of the community.

We strive to create an environment where members will feel comfortable and secure. We will not tolerate acts of physical violence, intimidation, or discrimination based on age, gender, ethnicity, sexual orientation, or disability.

The cooperative will maintain an agreement with NABORS, a unique and innovative model of support for people with disabilities. NABORS will provide the formal support services as required by some members in order to enable them to live in this community (e.g., attendant care, homemaker assistance, etc.).

The co-op recognizes the responsibility of promoting:

- good citizenship within the neighborhood of North Toronto and the City of Toronto;
- cooperation with other members of the broader cooperative movement.

together for 5 years to make their vision for a co-op into a reality. As Sonya, one of the Board members, remarked:

> The time it took was frustrating, at times; there was always some setback. But, I'm glad I stuck it out. I knew other people, this was not for them, they were so badly in need of housing they couldn't wait.

Co-op subsidies. In Canada, co-ops receive certain amounts of subsidies for some of their units, ranging from shallow to deep subsidies (shallow being a smaller amount of subsidy; deep being a greater amount). The city determines this mix of shallow versus deep subsidies. Most of the subsidies are shallow ones, whereas most of the people who inquire about units with subsidies need the deep ones. Since people with disabilities typically have limited financial resources, Board members made the decision to put the people supported by NABORS on the priority list for subsidies.

Membership issues. Board members have struggled with how to select members for the co-ops. Their vision and intent is to create communities that are diverse along many dimensions. For example, they were clear, from the start, that they wanted to limit the number of people with disabilities supported by NABORS to 12. They have also been clear about wanting people representing a mix of socioeconomic groups, not just those who are financially very needy. At the same time, they have a hard time turning people away who are too financially needy to afford this co-op.

Board members struggle with figuring out how to select people who are really interested in relationship and community, and not just a cheap place to live. However, as Sonya put it:

> We hesitate to develop criteria such as you had to have had a relationship previously with someone with a disability. Rather, part of it is faith; a belief that, within people is a wanting to relate to other people.

As a strategy to further get to know people, members of Courtyard and CHORD decided that once people are accepted for membership in the co-op, even if there is not an immediate opening for them to move in, they will be expected to join in community activities, to be part of things, while they wait: "We hope that this will give them an opportunity to see whether this kind of life is what they want, as well as giving us an opportunity to get to know them."

Sonya, one of the Board members who interviewed people for membership in CHORD, described how she tried to look at people:

> I don't look for having a good job, or having money, because we seldom get people like that. Or, people who can verbalize themselves adequately, I don't look for that. I try not to get caught up in that, with people who can say the right things. I try to look for the simplicity in the person. And, more of a feeling, their willingness to learn, to know, or to want to know. So, that's what I look for. Because

> sometimes people can say all the right things, so I try to look beyond that. You know, what is the person willing to give to the community, and what do they need from the community. Most people come without much of an idea of what intentional community is, and you can't just give that to them in an information session. I look for the people who will ask questions and say, "That sounds wonderful!," or even the people who are skeptical and say, "Do you think this can really happen?" I say, "We can make it happen."

NABORS: Support for Full Participation

One of the keys to making this co-op effort different from most other co-ops is the commitment to support the full participation of people with disabilities. As one advocate observed:

> Being in a co-op means nothing, unless there's support to participate. There are a couple of women that live in Courtyard that used to live in a co-op; they lived together in that co-op and had SIL (supported independent living) support. And they were lonely and isolated. Their story is the same as the story of another couple that live in Courtyard that lived in a high rise private rental building. They were lonely and isolated and didn't know any of their

neighbors. So, yea, being in a co-op means nothing, unless there's support.

This will be accomplished both through informal connections and networks as well as the more formalized structure of NABORS.

NABORS is an entity that is based on the following principles: community, natural social support, participation, self-determination, and nondiscrimination (see Figure 2). In conjunction with the co-ops, NABORS serves a number of purposes. As previously noted, one is to uphold the vision of individualized personal support and community building. It also acts as a vehicle for funding supports for the 12 people with disabilities who will be part of both co-ops. Many of the people who are or will be supported by NABORS have become part of its Board, making it increasingly an organization directed by people with disabilities.

There has been some discussion about whether NABORS should be a separate entity at all, or whether the support it provides should come through the co-ops themselves. For the time being, it seems as if there is a role for NABORS as a separate entity, both in dealing specifically with funding issues for paid support, as well as for helping to guide people's thinking about inclusion of co-op members with disabilities.

In Ontario, the government does not fund people with disabilities directly. Typically, funding is linked to places, or facilities, versus individual people. Formulation of this project involved challenging the government to look at people as individuals, instead of by label. The funding mechanism that resulted is not entirely

FIGURE 2

NABORS PRINCIPLES

Community

NABORS believes that all people strive to be with others in mutually satisfying relationships, and that a community developed from these interdependent relationships is strengthened in the celebration, nurture and sharing of each one's gifts, enhancing the unique qualities of the individual.

NABORS, together with the members of CHORD and Courtyard Cooperatives, will provide each person with opportunities to be included and to contribute to community life, both within the co-operative and in the community beyond, and ensure that appropriate personal support is available at a level to facilitate that participation.

Natural Social Support

NABORS believes that each of us needs, desires, and hopes for the company and friendship of others, and the love and commitment of family and close friends, and that natural relationships are essentially more meaningful than paid companionship.

NABORS will assist in building mutually supportive relationships among all members of both co-operative communities as well as in the community at large. NABORS will value and respect relationships with family and friends.

Participation

NABORS believes that a community needs all its members, and that people who have in the past felt isolated and rejected must be welcomed by the community to participate. This means being asked to share ideas, gifts and abilities with others, for the benefit of the community.

NABORS will assist members to participate effectively in co-operative meetings and activities, to join groups, associations, clubs, and churches, and provide, where necessary, the personal support to make this participation possible.

FIGURE 2 (continued)

Self-Determination

NABORS believes that each person needs to have rich and meaningful experiences, and to make self-determined choices.

NABORS will assist people to gain, regain and preserve power and control in their own lives, communicate their choices and preferences, as well as their fears of abuse of all kinds. We will listen and respond. We will provide access to both technical advice and advocacy.

Nondiscrimination

NABORS believes that for community to be competent and caring it must meet the needs of all of its members.

NABORS will ensure the inclusion of all members regardless of the nature of a person's disability or whatever other label has been previously acquired as citizens in the community of the co-operatives.

individualized, but was a step in that direction, with the money going as a block of funding to NABORS. In addition, it is not tied to the place, but rather to these 12 individuals. It is the first project in Ontario funded by two different government ministries--the Ministry of Health, which traditionally funds attendant care for people with physical disabilities, and the Ministry of Community and Social Services, which traditionally funds people who have intellectual disabilities.

The funding comes to NABORS and is divided among the 12 people. However, there is flexibility for people supported by NABORS to make changes in this division of money based on changing needs or desires. The money is intended as support money--that is, to support people to participate, whatever that means for a particular person--whether it be getting out of bed in the morning, attending a committee meeting, or socializing with friends and neighbors.

Another purpose of NABORS is to support the community connections and social networks of people with disabilities. The intention was that those who are supported by NABORS would already have support networks in place, though some of these are limited and need strengthening. NABORS anticipates playing an active role, working in conjunction with the larger co-op membership, in helping to expand and strengthen people's networks. At the same time, the concerns and fears of parents are acknowledged:

> Parents' main concern is safety; they see relationships as icing, not the cake. They're not sure about the community part. They've gotten desperate. We're asking them to do a

> 180 degree, and it's difficult. They want the coop to play the role of a service provider, telling people what and what not to do, but people in the co-op don't want that role.

From the start, those who are developing this project have been clear that NABORS is not intended to play the role of the traditional service system, taking over accountability for people's lives. As one member put it:

> And where's accountability? I mean, we pay the bills. Does this make us accountable? Well, some people would like to think it does. But really, what we're saying is we can't be that way. It's got to be the support circle and the person, with us in there, too.

Those who have worked to develop NABORS recognize there are certain elements of traditional service provision in the support they will generate for people: "They need to know when the next person's going to come to support them, if they need assistance to do something." However, they are also conscious about wanting to be different from traditional service agencies. The process of clarification of what this means has taken time. As Beth explained:

> One thing we're pretty clear on now is the ways we don't want to be like a traditional service agency. If we were to take on that traditional service role, we might be inclined to try to solve everything. So, you have to be pretty clear as an organization about what you are and what you are not.

> But, life is a dialectic process. You can't always be clear about everything all at the same time. So, you kind of do a few things and something happens. You have to step back and figure out what that was.

Overall, the NABORS structure is based on the idea that supportive relationships are not just a nice thing in people's lives; they are essential to people's lives. As Linda, a "community facilitator," put it:

> One struggle has been and continues to be helping people to understand that this is not icing on the cake; that the NABORS support model is based on and depends on the support networks. Typically, relationships have been seen as luxury items; and, in this model rightly or wrongly, that's not our way of thinking.

Thus, the NABORS idea is closely tied to community building, or intentional community, among all people in the co-op, not just for members with disabilities. Some of these efforts are described in the following section.

Building Intentional Community: Tending to the Social Architecture

Community building and the development of intentional community are seen as keys to this effort, making it distinct from most other co-ops. As one person put it, "The intent of this project is for people to live cooperatively, not just manage cooperatively."

People who are involved in this project believe that within all people there is a desire for deep connection and a sense of community membership. To illustrate, they give examples of how other members of the social networks of those moving in have decided that they, too, want to move in:

> We've seen that evolve with some of the individuals who NABORS is supporting like Fred. He was going to move in. His mother is very active in his life. When she went to look at the building, during the construction process, she decided she was going to move in too. Then, before we knew it, his sister who has five kids decided she was going to move in there too. And then the woman who provides his home care also decided she was going to move. So, literally, his whole network.

Thus, it is clear that they are creating something here that is attractive to many people.

They emphasize their feelings that there is not one single model or way to go about community building; it is a very context-specific and people-specific venture, based on the particular group of people engaged in it. And, they recognize that it entails hard work. As Audrey, a co-op member and community facilitator at Courtyard, put it:

> I think about it being sort of like the smell of homemade bread. You know, everybody wants it, and everybody likes it, and everybody says, oh, isn't this great, but there's some

> real struggle with it--is it going to be a priority for your life. There's a danger of making it sound like a romantic kind of feeling, as opposed to something that's--it's very tough.

For some of the members of the co-op, the idea of intentional community is radically different from how they were raised and the culture they are immersed in. Audrey commented:

> We're really swimming against the tide in so much of what we're doing that we need all kinds of ways to come back to what we're trying to do. Because we've all practiced for years how to do it other ways.

For other members, intentional community is not new, but is similar to what they experienced as a way of life in their own culture. As Sonya reflected:

> I'm from a culture from a small island in the Caribbean called St. Vincent. When I was growing up as a kid, if you were a fisherman and I was a seamstress, I would make the clothes and he would bring me the fish. If you weren't at home, and I needed some salt, I would go into your kitchen and get some salt. People didn't pay babysitters because if I was going to the market, my neighbour or friend will keep an eye on the kids. Now, for my kids, here, growing up, in four years, you say "Hi," but you don't know your neighbours' names, they don't know yours.

In order to support the community-building vision, a number of things have been built into the co-op organization. First, because people felt it was as important to attend to the social architecture of the community as to the physical, they wrote a grant and received federal funds for two "community facilitator" positions. Audrey and Linda described two basic components of their work as community facilitators: (1) thinking about the community as a whole--what is it about, how can we support it in coming into actuality, and how can we help people feel as if they are a part of the community; and (2) helping people supported by NABORS to be part of the community, which includes helping families deal with the realities and struggles of life here. They feel that one of the keys to their effort is having a core group of people who understand the concept of intentional community, so they can together assist others in the process of coming to a similar understanding.

In addition to the use of community facilitators, numerous other strategies will be used to foster a sense of community. For example, among the committees is one called the Community Committee, which is responsible for planning social events and thinking about other ways to increase people's connections. Community retreats and meetings are scheduled regularly. Those they have had so far have helped them think in more inclusive ways about each other. For example, Audrey commented:

> In meetings, we need to get used to the mix of cultures. At the meetings, families bring their children, which probably isn't as much the North American way, which would be to get

> a babysitter. We were constantly forgetting that, that the children will come.

Now, they plan meetings with the children in mind.

In the Courtyard community, people reflected on the connections they see being made. Audrey observed:

> People are beginning to see past the exterior that we all have, to become more aware of the vulnerabilities of people. What is happening is a deep interacting that is very mutual.

And, Gillian shared some observations of her daughter, Kerrie:

> She can't shop by herself, but somehow her shopping is getting done. And, she knows how to use the bank machine, but she won't use it alone. She's scared of something going wrong, and she can't read what's wrong. But, there's always somebody who will go over to the bank with her.

Finally, NABORS has played an active role in assisting people to think about community building among all members of the coops. As Audrey put it:

> The co-op community has lost it's roots, in some ways. It's like coming back to the river, in the sense of coming back to what we need, with intentional community. And, it is

> NABORS that has been really thinking about this. They have some principles, and they have really given nourishment for intentional community.

And, Linda added:

> Over time, the principles from NABORS will hopefully be more widely elucidated and internalized. For now, NABORS can act as sort of a keeper of a vision; because, in the bottom line, NABORS is the organization that has committed to those 12 people.

Conclusion

In the midst of many day-to-day decisions and activities revolving around the co-op and NABORS, participants have maintained their vision by focusing on:

- ORGANIZATIONAL CLARITY--particularly about the role of the co-op and NABORS in people's lives, versus traditional service agencies;
- INTENTIONAL COMMUNITY--versus just cooperative management of housing;
- FULL PARTICIPATION FOR EVERYONE--with the support needed for this, versus just physical presence or limited, sporadic participation;
- RELATIONSHIPS--as central to people's lives, not peripheral.

The story of this co-op effort does not have a particular end or result. Rather, it is the continually evolving story of how people with and without disabilities, parents,

advocates, friends, and neighbours continue to build community for and with each other.

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